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Prue, G., & Santin, O. (2014). Assessing the Needs of Informal Cancer Caregivers: A Review of the Instruments and Recommendations for Use. *Psycho-oncology*, 23(s3), 78-79. <https://doi.org/10.1111/j.1099-1611.2014.3694>

Published in:
Psycho-oncology

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
[Link to publication record in Queen's University Belfast Research Portal](#)

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This is the peer reviewed version of the following article: (2014), Oral Abstracts. Psycho-Oncology, 23: 65–168, which has been published in final form at <http://onlinelibrary.wiley.com/doi/10.1111/j.1099-1611.2014.3694/abstract>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

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Assessing the needs of informal cancer caregivers: a review of the instruments and recommendations for use.

Gillian Prue, Olinda Santin
Queen's University Belfast

Background

Caregivers of cancer survivors report reduced levels of physical and psychological health long after cancer treatment has ended. Their concerns can be estimated via various patient reported outcome measures. One such method is needs assessment. In order to conduct valid and reliable cancer caregiver needs assessment, the selection of an appropriate tool is paramount. This review aims to support researchers and clinicians in their choice of self-report tool for the assessment of cancer caregiver need.

Methods

An electronic database search of Medline, CINAHL, PsychINFO, Internurse and ProQuest was conducted. Included studies focused on the psychometric properties of needs assessment tools of caregivers of cancer survivors. Studies measuring quality of life (QOL) or satisfaction with care were excluded. Studies examining the needs of caregivers of advanced/terminal cancer patients or at bereavement were also excluded. Evidence for internal consistency, test-retest reliability, content, criterion-related and construct validity and responsiveness were summarised for each instrument from the information available. Information on clinical usefulness; namely acceptability (percentage completion), length, response format and time for completion was also extracted.

Results

Seven assessment tools were identified. Data on instrument development was well reported, with the majority having support person/caregiver input. Variability was noted in the structure and content of the tools. The majority demonstrated some degree of reliability and validity; all measures demonstrated internal consistency but only two were evaluated for test-retest reliability (CaSPUN and SPUNS) with only the SPUNS showing reliability over time. Four tools (CaSPUN, CNAT-C, SCNS-P&C and the CaTCoN) showed evidence of group differences validity. The HCNS, NAFC-C and CaTCoN have been validated at various stages of the cancer continuum. Minimal data was available on responsiveness.

Conclusions

The seven instruments were not site-specific and therefore could be used to identify needs of caregivers of individuals with the most common solid tumours. General measures may not highlight certain issues that providing care for a specific cancer type may present. It may be necessary to develop 'add on' tumour specific modules. All tools identified require further psychometric analysis. The NAFC-C demonstrates a great potential in both the research and clinical environments, however it requires further psychometric testing before it can be fully recommended. Further analysis is necessary on response formats and the meaning of a total needs score.

Research implications

For research purposes, given its rigorous psychometric testing, and the fact it has demonstrated test-retest reliability and hence would be effective in tracking changing needs with time, the SPUNS is considered the most appropriate. However, given that it consists of 78 items it may be too long for clinical use.

Clinical implications

Clinically where needs assessment would be used to triage caregivers and assist clinicians in referring caregivers to appropriate services, the shorter CaSPUN or SCNS-P&C may be more acceptable, although the population to be assessed should be taken into account; the CaSPUN

has been developed for partners only, the SCNS-P&C for both partners and caregivers, and therefore would be considered the most useful (although it has only be validated in the early survivorship phase).